**United for Lifesaving Research: A Collaborative Call to Defend NIH Funding**

The MSUD Family Support Group believes that research is the key to improving the daily quality of life for individuals and families living with MSUD. Recently, we championed support for research by drafting a letter advocating for sustained federal investment in rare disease research—a letter that has been endorsed by several allied organizations. This collaborative effort reflects our shared commitment to advancing treatments and improving outcomes for those affected by rare diseases.

On behalf of the undersigned organizations dedicated to advocating for individuals and families impacted by rare diseases, we express our deep concern over the proposed funding cuts to the National Institutes of Health (NIH). The suggested policy change to cap indirect cost funding threatens to strip essential research institutions of the resources they need—resources that are vital for maintaining laboratory space, equipment, and staffing. Without these critical supports, groundbreaking research that provides hope to millions of Americans could be delayed or even halted.

Rare disease research already faces unique challenges due to the limited number of patients affected by each condition, making sustained federal funding an indispensable lifeline. The NIH has long been instrumental in driving discoveries and therapeutic advancements, particularly for conditions that receive little private investment. A reduction in funding would not only jeopardize current research projects but also undermine future innovations, with serious repercussions for the broader rare disease community.

Beyond the impact on research institutions, the proposed funding cuts carry significant economic consequences. Rare diseases impose a heavy financial burden on society, with per-patient costs far exceeding those of more common conditions. Reducing NIH funding risks exacerbating these challenges by stalling progress that not only saves lives but also sustains economic stability through job creation and continued innovation in medical research.

Sincerely,


Maple Syrup Urine Disease (MSUD) Family Support Group
Sandy Bulcher, MSUD Board President